

between countries. I assume, although this is not actually stated, that it is intended as a comprehensive survey.

The first thing that strikes me, as a worker in the IVF field in the United Kingdom, is that we alone in Europe have no system for financial reimbursement of our clients. Not only is there no provision through the National Health Service, but the private health schemes in the United Kingdom contain exemption clauses for this treatment. I feel that IVF is now standard treatment and arguably the most effective medical intervention in infertility and should be recognised as such under the National Health Service. It is interesting that the research project was funded by the Department of Health and I hope it is considering righting this anomaly.

There is however no explanation of the reason for the support of the DHSS and this proves eventually to be a frustrating aspect of the book. Nowhere does the author say why the project was undertaken, nor does she discuss her findings. There is a chapter on the need for uniformity under the Council of Europe and Ms Gunning explains the usual process for obtaining consensus and the role of the *ad hoc* Committee for Bioethics. Perhaps the data was collected to inform this committee and it certainly shows the great disparity between the member states of the European Community. But this does not explain why the data from Australia, Canada and USA is included. If the data is intended to be complete then the data from Austria should be included. It is also frustrating that having discussed in some depth the legal situation in all the other countries the author does not give the same attention to the United Kingdom data, merely including it in the tables.

[Though it should be added that the position of the law here is difficult to determine until implementation of the Human Embryology and Fertilisation Bill].

The book will however be useful to people working in the IVF field just for the raw data it contains. I personally shall also find it an intriguing pastime analysing the consistency in policy for each country between embryo research and abortion and making associations between, for instance, the population policies and religions of those countries.

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Assessing Quality of Life

Edited by Stefan Björk and Johannes Vang, 104 pages, Linköping, Sweden, \$25, Linköping Collaborating Centre, 1989

This volume is the first in a planned series of Health Service Studies from a WHO collaborating centre at Linköping University. In eight chapters it presents the proceedings of a conference of quality of life (QOL) hosted by the Centre for Medical Technology Assessment at Linköping University. The first three chapters are conceptual and philosophical, attempting some semantic 'ground clearing' on the origins of, and relationships between, concepts of QOL, happiness and social welfare. The remaining chapters focus on the practical issues of how and why QOL should be measured in health care evaluation studies, particularly in clinical trials, and the way in which a composite indicator of health outcome – the ubiquitous Quality-adjusted Life Years (QALYs) – could be used to prioritise the allocation of scarce health care resources.

Given the focus on health care, the book might benefit from an early distinction between QOL as a general concept and so-called health-related QOL. Initiatives to quantify the latter find origin in measures of functional (physical, emotional, social, etc) status and activities of daily living, whereas more global concepts of QOL would embrace a wide variety of influences on life satisfaction that may have little or no relationship with a person's health status. (The fact that I cannot afford a new BMW may have a modest negative effect on my global QOL but is not having any discernible impact upon my health status.)

Readers not familiar with the QOL literature are spirited rapidly and somewhat uncritically through the various QOL instruments such as the Sickness Impact Profile (SIP) and the Nottingham Health Profile (NHP). There are important differences between these two instruments that potential users should be made aware of – while it is possible to compute an overall SIP score (over all domains), this is not possible with NHP. Thus in a trial of treatment A versus B, each of the six NHP domains (for example pain, physical mobility, etc) would be computed separately for each treatment and any definitive statement of overall

health-related QOL superiority would require one treatment to be superior in all six domains.

A major omission from this volume is any discussion of utility measurement techniques such as standard-gamble and time-trade-off which are being used increasingly to construct composite health indices combining survival and QOL according to patient preferences. The uninformed reader might be forgiven for thinking that QALYs can easily be calculated from some combination of SIP or NHP and survival data, but this is not the case. The construction of QALYs requires somebody, somewhere, to make an implicit or explicit trade-off between combinations of quantity and quality of survival.

The use of QALYs by health economists raises a number of philosophical questions which are only briefly addressed in this volume. The ethical foundation of economics is a concept of social welfare based upon utilitarianism – the greatest good of the greatest number. But this efficiency criterion is silent on issues of equity or distributive justice. Prioritising health care interventions in terms of their cost per QALY assumes that society places the same value on one QALY gained irrespective of whom receives this benefit. In some situations society may prefer to forego some efficiency to gain distributive or fairness objectives. Such efficiency-equity trade-offs are a challenging area for future research.

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The Social Consequences of Genetic Testing

Edited by H Rigtter, J F C Bletz, A Krijnen, B Wijnberg and H D Banta, 106 pages, The Hague, Holland, available free on application to Scientific Council for Government Policy, PO Box 20004, The Hague, The Netherlands, the Netherlands Scientific Council for Government Policy, 1990

This useful text is the edited version of the proceedings of a conference held in Leidschendam on 16–17 June 1988. Genetics and genetic testing and the

likely consequences of such genetic material becoming more widely available to society are issues which are highly relevant. The contributors to the book come from a wide-ranging spectrum of interests – medical, legal, sociological, patient and workforce, and their papers, read consecutively, present a thoughtful and broad-based perspective of the problems that society will have to confront more and more in the days ahead. As huge sums are spent on trying to unravel the mysteries of the human genome, anxiety is beginning to surface on the question of how far individual genetic information should be kept completely confidential and how far it should be made available, for example as a result of medical examination for life-insurance, employment and pension schemes.

In his introduction, MF Niermeijer, points out that 'errors in specific hereditary traits (genes) are present in one per cent of newborns. They are often transmitted according to a predictable hereditary pattern. This is now known to be the case for about 4,000 genetic disorders'. However, genetic counselling could not prevent the birth of all 'defective children'. In Holland, it is thought that out of about 9,000 children born annually with congenital and/or hereditary defects, only 500–800 births would be detected as a consequence of risk limitation following genetic counselling – an 'important but modest preventive effect...'. The majority of these defects are caused by an unpredictable error in the formation of the sex cells, a combination of genetic factors from two healthy parents, a disturbance during early pregnancy, or complications during or just after delivery. Thus, there is no basis for the belief that the application of modern technology might lead to a society without handicapped people. What is important is that those parents who may be at higher risk are informed in time about the risks and the possibilities of prevention.'

These are very important considerations to bear in mind when assessing the impact of such information for society as a whole. For individuals who can be identified as likely or certain developers of chronic, disabling and terminal diseases, the revelation of this could have deeply negative effects, both psychologically and for the purposes of insurance and employment. At present, the text tells us, insurers pool their risks and adjust their premiums accordingly, though they may make adjustments to take

account of medical data available and an individual's life-style, for example whether he or she drinks or smokes.

Insurers would therefore be keen to have available any extra and more accurate genetic data to help evaluate the particular insurability or employability of an individual and thus the chance to offload individuals with a known high risk. How far the law or practice should prevent this happening remains debatable and there was no absolute consensus from the contributors. The competing interests of different parties will have to be weighed in the balance very carefully, and particular care given to ensuring that if genetic information is made available i) it is very carefully interpreted, and ii) it may not be used in a manner that creates two classes of individuals, those regarded as genetically 'fit' and 'unfit'.

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Talking and Listening to Patients – A Modern Approach

Charles Fletcher and Paul Freeling,
68 pages, London, £2.50, Nuffield
Provincial Hospitals trust, 1988

In many ways, this is a very useful little book. It is deliberately kept short, to be a handbook for students in learning to deal comfortably with patients, both in listening to them and talking to them, and it emphasises time and again that listening to patients is a large part of the art of communicating with them.

There are, for instance, excellent examples of how this may best be achieved. There is the suggestion that patients should be asked to repeat back to doctors what they have just been told, a good way of discovering whether the patient has understood, and of finding out if there are other concerns as yet unexpressed. The doctor is encouraged to sit down with the patient rather than stand, and bad manners are roundly, and rudely, condemned.

But there are problems. Whilst the authors advocate providing patients with far more information than has hitherto been the norm, when they come to discussing what to tell terminal patients, a section of the book which is

sensitively written, they nevertheless justify a certain amount of disinformation. They do this by arguing that 'students must realise that there are no rules except that hope must never be extinguished', (page 40). They cite a distinguished source, one T B Brewin, but whoever they cite, their assertion needs careful analysis. For it may be appropriate, though painful for the doctor, to extinguish hope of a long life when a patient is near death.

The reasons are many. One is that the hope may be a defence against acceptance; it therefore requires careful handling to make that sort of decision, where a patient is indicating that she or he does not wish to know. But, more importantly and more frequently, there are those who do wish to know, who do want to know, literally, that their case is hopeless, so that they may make arrangements for their loved ones and set their affairs in order. It is precisely because hope is no longer a reality that many of those terminally ill come to terms with their final arrangements, as well as sometimes fulfilling some long-held ambition.

It was surprising to read this in a book which also makes it clear that patients' families should not be told too much, so that they are not in that terrible situation of knowing more than the principal protagonist, the patient. But there is an underlying instruction to be kind and gentle in this volume, which is occasionally not sufficiently toughened with an instruction to face the worst, the most hopeless, of prognoses. That apart, this is a book that every medical student should receive free at the beginning of training, and be tested on at frequent intervals. For the message, the necessity of learning to communicate with patients – is simple, and one would have thought glaringly obvious, but sadly far from frequently observed in practice.

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Principles and Practice of Forensic Psychiatry

Edited by Robert Buglass and Paul Bowden, 1584 pages, Edinburgh, £150.00, Churchill Livingstone, 1990

This book is, as claimed by its foreword, undoubtedly a landmark in